Currently I am in the planning stage of a research project on palliative care at home, and I will first present the research topic – complementarity of primary caregivers and health professionals in end-of-life care of people with amyotrophic lateral sclerosis (ALS) – and its objective. In reviewing the state of research in medical, psychological, anthropological and nursing science literature, the role of support or self-help groups in palliative care appears to be neglected. Would comparing self-help groups for people with a life-threatening illness and their kin as found in Switzerland to sociotherapy in Rwanda bring overlooked insights? This question will be addressed at the end of this essay.

Although focused on personal well-being and meaning in life instead of curative treatment, non-cancer palliative care can still occur alongside care that may be curative in approach. In palliative care, not only are the most diverse professional groups in the areas of health care, social work and counselling involved, but it distinguishes itself moreover by the inclusion of lay people and family members. On the one hand family members share in a majority of the outpatient care, while on the other hand the next of kin themselves present a target group for receiving psychological and social support in managing the burden as the disease progresses, as well as bereavement counselling. In 1990, the goal of palliative care was defined by the WHO as restoring and maintaining the best possible quality of life in the sense of emotional, spiritual, social and physical well-being for patients with a progressive disease and a limited prognosis. Patients with ALS, the most common form of motor neuron disease (MND) in adults, fulfil these criteria from the very moment of diagnosis (Borasio et al., 2002). There are no effective treatments to stop or reverse the course of the disease, which leads to death usually secondary to respiratory failure after an average of 3 to 5 years. However both its course as well as its survival varies considerably. People with ALS become severely disabled as the disease progresses. ALS has
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an incidence rate of 2/100,000 per year and a prevalence of approximately 8/100,000. In Switzerland there are circa 700 people living with ALS, in the Netherlands roughly 1000, in the UK around 5000, and in Germany about 6000 people. This chronic, progressive neuromuscular disorder is rather rare; nevertheless Borasio et al. argue that ‘ALS is particularly suited as a model for palliative care research’ (2002, p. 105). It is not its prevalence which legitimizes it as the focus of research, but rather the high level of demands to which ALS patients and their families in palliative care are confronted.

Of central interest for the project to explore is what constitutes quality end-of-life care in ALS at home. One of the requirements for effective palliative care is a good relationship between health professionals and the family caregivers of persons at the end of their life, which also applies to the situation at home. The focus of the research is therefore directed in particular at the close interaction of family caregivers and health professionals in caregiving at home. Pressures on long-term care systems are set to grow (Colombo et al., 2011) and likewise in Switzerland the demand for home care will rise (Höpflinger et al., 2011). Starting point are the following assumptions: (1) that as a result of the cost pressure on the health-care system, the role of informal care will become increasingly important; (2) that the area of contact between family caregivers and health professionals is not personally but rather structurally conditioned; (3) that different positions and clashes occur at the cost of good palliative care at home; and (4) that a balanced dying process has an effect on the mental health of the family caregivers. Based on these it would follow that possible causes of conflict and boundary-crossing, such as lacking respect for patients’ self-determination, but also empowering practices should be examined from multiple perspectives, including from the points of view of family caregivers, patients and health professionals. Ultimately the concern is to optimize the care of patients by exploring how family members can best be supported in providing care at home. Fundamental to this aim is to study the binding forces among the multitude of different actors that produce palliative care at home in terms of cooperation as well as conflict. Gender pervades care. Home care is not solely, but primarily facilitated by female family members. This might influence communication patterns with health professionals or decision-making processes.
ALS patient palliative care and caring for the caregiver

Clinical literature on palliative care in ALS is diverse and covers provision of care in areas such as symptom control, medical and palliative interventions and management strategies from diagnosis to bereavement, as well as research on provision of care related to ALS survival. Management issues include how to deal with communication difficulties, respiratory dysfunction and nutritional requirements. Legal and ethical issues involve advance directives and advance care planning decision aid, or factors underlying end-of-life decisions. Terminal phase in ALS and place of death linked to Preferred Priorities of Care are focused on. At the same time there is a strong interest in quality of life assessment along indicators like depression, anxiety, social isolation and suicidality in ALS. Moreover, the psychosocial impact of ALS on patients and their partners in areas such as sexuality, its economic impact, or its impact on healthcare professionals is also of interest. The concept of hope in palliative care is an important and rather neglected area of psychotherapeutic research (Breitbart et al., 2003); nevertheless some research has been done exploring the meaning of hope in individuals with ALS. Fanos et al. (2008) for instance, underline that patients draw upon a variety of mechanisms to sustain hope when facing chronic disease, including hope for a cure (as meant by Sigurdsson, 2011), social support, seeking information, spirituality, limiting the impact, adapting to changing conditions, living in the moment, and transcending the self. Likewise researchers are keeping both a close eye on distress as well as on resilience – referring to the human capacity, despite risk and extremity, to face, overcome and be strengthened or even transformed by experiences of adversity using individual and social resources – among patients with ALS and their caregivers (Wasner, 2008). Rabkin et al., (2000) identify spirituality, religiosity and meaning in life, along with family or other social support as protective factors. Consistent with these dimensions of resilience are several hope categories analysed by Fanos et al. (ibid.). Risk factors include illness symptoms, suffering and pain, ventilator dependency, and perceived family burden (Rabkin et al., ibid.).

Palliative care professionals, in Australia and Germany for example, receive information about ALS and training, caregivers in the USA are supported by formal training, and in Switzerland training programmes target ALS patients, caregivers and healthcare professionals. Caring for the caregiver is emphasized not only with a focus on the danger of burnout for family caregivers, but also on their problem-solving skills linked to quality of life and psychological morbidity, or on disparities in perceptions of dis-
tress and burden in ALS patients and family caregivers. Researchers have developed interventions for ALS caregivers, such as the Caregiver Assessment Questionnaire (Bremer et al., 2010) to identify caregivers’ needs. Recently a multi-perspective qualitative study explored the diagnostic experience for people with ALS, as well as for current and former caregivers (O’Brien et al., 2011).

Anthropology of the ends of life and home care ethnography

Anthropological attention to the ends of life (Kaufman et al., 2005) is strongly focused on communication about and during end-of-life care. The culture of medicine is examined, for example, in a study on the impact of patient death on physicians and the implications for the quality of care at the end of life through an analysis of how physicians from two major academic medical centres in the United States tell stories about the deaths of patients under their care (DelVecchio Good et al., 2004). Further examples are investigations particularly with regard to the cultural construction of different forms of dying as either ‘good’ or ‘bad’ (Seale, 2004) and ethnographic accounts of end-of-life discourse in the Netherlands (Norwood, 2009). The significant role families play in end-of-life decision-making is seen as one of the key emerging issues (Gordon, 2004). There is substantial Medical Anthropological research on cultural diversity within the same society and end-of-life care (Pool, 2004; De Graaff et al., 2010). With hospital ethnography in its infancy (Van der Geest et al., 2004), a new field and interest in patients’ perspectives on hospitalization is being discussed, including fieldwork in wards and clinics (Long et al., 2008). In high-income countries the focus is increasingly on dementia (McLean, 2007; Droz Mendelzweig, 2009). Until just recently, it could be said that home care ethnography either focused on terminal oncology patients at home (Pols, 2010) or on patients with a progressive neurodegenerative disorder (Verwey, 2010). Although medical anthropologists have been doing research in Western societies for almost four decades, research in one’s own society has only been labelled ‘at home’ for a dozen years.

Multidisciplinary care, case management, care and conflicts

Good management of patients with ALS involves a hospital and community-based multidisciplinary team. The nursing research perspective covers
key areas in management of patients with ALS, including the role of the nurse and the importance of a well-coordinated multidisciplinary team. Conflicts of interest are indeed considered but are restricted to the relationship between close relatives and patients in ALS. Palliative care of chronic conditions means besides practical help, also trusting relationships and enhancing family caregivers’ involvement through training and support (Goldman, 2009). Although family-based palliative care is a great concern of ALS nurses, except for the development of interventions, no research exists on how the cooperation between professionals and family members works at home. In general, family care research is applied to effective case management to bridge ‘troubled waters’ (Levine et al., 2010) and to make sure that family caregivers are treated as important care partners. Studies broaden the view on informal caregiving from the micro level, where individual caregivers attempt to face the responsibilities of caregiving, to the macro level of the health care system to find more effective ways to support family caregivers (Arno et al., 1999). The political and social economy of long-term care has recently been studied in several countries by OECD (Colombo et al., 2011). In the French-speaking part of Switzerland, ongoing studies focus on conflicts and their implications for end-of-life care from the professionals’ perspective (Mpinga et al., 2009). The family caregivers’ perspective on cooperation and conflicts in end-of-life care is an original, uncovered field of research. Its contribution of self-help or support groups – not only to the quality of life but also to individual and social strength – is a neglected topic of research as well.

**Self-help groups as a supporting factor – in which sense?**

Support groups appear to be touched upon en passant in research on ALS patient palliative care. However there is evidence that participation in such groups is advantageous (Goldstein, 1998). Self-help groups are seen as a supporting factor in the quality of life of people with ALS and caregivers. Is there more beyond this functional perspective? In most high-income countries in which an ALS/MND Association is located, self-help groups have been set up. As the progression of the illness requires ongoing adaptation, the meetings are quite practice-based and often structured around either contributions of guest speakers or by sharing information and experiences. They offer opportunities to discover that one’s feelings of anger, hope and sorrow are familiar to others, which can reduce social isolation.
Research on both high-risk children from birth to adulthood and on trauma survivors is emphatic about resilience and its protective factors. The same can be said of psychosocial research on ALS patients and their families as shown before. This link motivated me to look more closely at sociotherapy groups in Rwanda as explored by Richters in several articles (2009, 2010; Richters et al., 2010a, 2010b). The universal ability to ‘bounce back’ after highly stressful or traumatizing events turns out to be an ongoing process for people with a life-threatening illness and their nearest ones.

Comparing self-help groups to sociotherapy

Community-based sociotherapy was introduced in Rwanda in 2005 in order to contribute to a new foundation for well-functioning communities. In sociotherapy groups the main concern is to help people start a process of integrating experiences suffered into daily life, and above all linked to reconciliation, in the sense of social reconnection, to accept those people who had been part of genocide in the past as fellow human beings in the future. The future is however not open-ended for people with a life-threatening illness, their friends and next of kin. One knows at some point sooner or later that the future will no longer be shared. So in both group settings the actual life situation is at stake. And both groups have to deal with great sorrow. Furthermore, instead of an individualized clinic and pathology-based structure, a group-based practice is effective. Sociotherapy as implemented in the north of Rwanda is structured by the set-up of weekly meetings of ten to twelve people per group, for approximately three hours over a period of fifteen weeks (Richters, 2010). Facilitators guide the group through particular phases of safety, trust, care, respect, rules, and memories along six particular principles such as interest, equality, democracy, participation, responsibility, and learning-by-doing. The specificity of sociotherapy compared by Richters et al. (2010b) to other interventions in post-conflict situations is its social rather than its psychological character. The same goes for self-help groups in terms of its social character, even though the setting is explicitly not therapeutically oriented. Whereas establishing a social network is a common feature of both group settings, sociotherapy seems to create a social space in which people come out of isolation and start to dialogue. And beyond that, Richters et al. write, a safe space is created where participants experience being cared for, which may facilitate a process leading towards reconciliation with their fellow human beings. Transposed to self-help groups, we could say that support groups create a social space
where participants experience trust mediated through the dialogue with others (often facilitated by a person close to them or by electronic communication devices, as speech may be deteriorating), which may further a process of coming to terms with the actual and future life situation.

It is its focus on the restoration of the damage done by political violence and its legacies to the fields of social relationships that distinguishes sociotherapy from self-help groups. Its primary aim is to repair the social cohesion. But both group settings share in its most important effect in that people realize they are not alone in suffering from particular problems. While sociotherapy supports an interactive dialogue, self-help groups on the contrary contribute to an internal dialogue. Living with a life-threatening illness implies a self-reflective reconciliation process.

**Individual and social resilience mediated by self-help groups**

Self-help groups for people with ALS, including their friends, family members, current and former caregivers as I got acquainted with them in Switzerland, usually meet every other month. The meetings of twelve to twenty people last for approximately three hours, and the facilitator structures the course of the session by asking each in turn the simple question, ‘How have you been since we met last time?’ Analogous to sociotherapy the principle of interest is practised. As Richters’ monitoring suggests, sociotherapy has the capacity to mediate other, often more top-down, programmes in the sense of enabling or strengthening the healing potential of these other interventions (2010). Self-help groups might in a similar way function for people with life-threatening illness as part of a social hammock in which individual medical care can be gently supported. Complementary to medical interventions, self-help groups in ALS palliative care foster individual strengths to bear times of despair with confidence – a process enabled by social resources such as sharing of information, mutual interest, and a sense of belonging together.

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